

Sarah Brooks - Written evidence (PRT0055)

The purpose of this submission of evidence, is to look into 'life beyond the Neonatal unit' and how the integration of services can improve patient's outcomes. As a Neonatal Outreach sister on a busy level One Intensive Care Neonatal unit, the discharge process is priority of care and is often an exciting and emotional time for both families and staff. As a member of the Outreach team, the healthcare worker is not only involved in the inpatient care but privileged to see the journey after discharge from the unit. Life beyond the Neonatal Unit is a new journey and often difficult to coordinate leading families to navigate systems with no clear direction.

Babies that are born preterm or have other health needs and require Neonatal admission are at greater risk of a number of further developmental issues (National Institute for Health and Care Excellence (NICE), 2017). NICE guidelines (NICE, 2017) explain that if a baby is born preterm they have a greater risk of disability or developmental delay. Some of the possible examples stated by NICE (2017) are cerebral palsy; motor function problems; learning disability; special educational needs; speech, language and communication difficulties; Autism; ADHA; feeding, sleeping, visual, hearing problems and the risk is greater depending on the birth gestation. From the above discussion, the outcome of future care will result in input required from NHS, Allied health, educational and social services.

Taking into account the preterm birth rate in the UK (60,000 babies) and the primary aim on inpatient Neonatal care of reducing morbidity and mortality, Healthcare workers need to look at life beyond the Neonatal unit, to improve integrated services and quality of life. By utilising services and policies that have already been implemented, or in a commissioning phase, looking to reduce parental anxieties and also the long-term health effects and education of the infant. It is important to have a safe, integrated discharge plan and support system in place, once

discharged from hospital, to act as a single point of access enabling adequate support for families to navigate systems. Therefore, policies need to be in place to support the infant's development through the uncertain initial years.

Under the Children and Family's Act (2014) local authorities are obliged to have accessible services that meet the need of those children with additional needs. With children being born prematurely, being at higher risk of disability and additional needs (NICE, 2017) the requirement for this specialist provision would be prevalent. Public Health England (PHE, 2020) discusses the term 'primary prevention', in which, focus on interventions put in place to address the root cause of health inequalities and determinants of health. In identifying these root causes of vulnerability such as preterm birth it gives the ability to plan care, offer early intervention and support.

Hua *et al.*, (2020) discuss the importance of streamlining discharge from Neonatal units, transitioning to home and home care, allowing for an integrated approach. The future needs of the family should be considered from as early as possible while preparing for life beyond the Neonatal unit and support available once discharged from inpatient care.

The 'Best start to life Programme (BSTL, 2022)' was launched with the aim of providing a single point of access to every family. Hancock (2021) recognises the importance of those first initial days, weeks, months and years and how they can impact on the child into adulthood. It is suggested that the programme focuses on the first 1,001 days in order to prevent poor emotional and physical health beyond this critical period. BSTL (2022) suggests that every child deserves the best start to life, regardless of socio-economic status of the family, which would include those babies that have been born preterm. BSTL programme (2022) focuses on 6 key action areas, all key areas have a significant impact on the future of any baby and family that have spent time on Neonatal Unit.

Much of the best start to life programme, has a focus on perinatal mental health and the effects of poor mental health on the family. Hames *et al.*, (2021) discuss the significance of hospitalisations negative impact on perinatal mental health and studied risk factors in special care baby units' stress levels from admission to discharge. Unfortunately, anecdotal evidence shows us the families do not feel prepared for discharge from Neonatal units and have an increased risk of anxiety once being on the unit, resulting in an additional disadvantage from the start. O'Higgins (2013) supports this by highlighting the importance of those first few weeks and how this initial bonding period can have significant impact on the parental mental health.

Hames *et al.*, (2021) also found that parental stress during the period of hospitalisation can have a huge negative impact on the infant's psychological and physical development. With preterm infants already being at greater risk of developmental delay parental stress could contribute to future health and wellbeing of the child. Burger *et al.*,(2015) carried out a survey looking at Neonatal parental experience and affirm that just over half of the parents interviewed felt that they had been given enough support with their mental health. With lots of focus around perinatal mental health and the impact on bonding, relationships and wellbeing of the family, the best start to life aims to reduce these health inequalities by commissioning services to work with families. Services such as Family Action (2023), a commissioned national charity working with communities and individuals, enhancing family relationships which they describe as the key to positive futures. Dickinson *et al.*, (2022) proposed that by screening for psychological distress during a Neonatal admission, support services can be made available post discharge which would optimize the functioning of the whole family unit. This support could be initiated and facilitated by the family hubs.

Specialist midwives, peer support workers and enhanced infant feeding key workers will also be commissioned by the best start to life. Breast

feeding and breast milk have many benefits for the mother and infant. The NHS Long Term Plan (2019) was set out to improve the quality of patient care and health outcomes, within the paper, benefits of breast milk are recognised and the need to enhance the support given to new mothers. Breast milk is encouraged on the neonatal unit and many units follow the Unicef (2022) guidelines. Establishing breast feeding can be difficult and often requires more support especially when they are discharged from a neonatal unit. Platt (2022) discusses these difficulties of separation on the Neonatal unit and how physical barriers such as touch and smell not only creates difficulties in establishing breast feeding but also can prevent parents from fostering a loving and responsive parent-child relationship. The family hubs offer a commissioned service to support families and new mothers so they can successfully breast feed in these first days, weeks and months. As part of the programme, commissioning has been provided for support workers to complete the Unicef training so they can support parents once discharged from hospital to effectively breast feed, improve experience and bonding.

The vision is that the family hubs would act as a 'single point of access' for families so that they can have access to services working together in a local, safe environment. Action two discusses the importance of the Multidisciplinary Team (MDT) coming together in local hubs, removing stigma and inequalities. The care of the infant in these early years can have many stakeholders such as physiotherapists, occupational therapist, dietician, and speech and language therapist, Psychologists forming a group with the same shared goal of achieving the best possible outcomes for the child.

Following the Okenden Report (2017) funding has been made available within the maternity and neonatal networks to fund extra allied health professionals within the NHS. Services that were historically unavailable or difficult to access have been recognized as essential in inpatient care. Speech and Language Therapists (SALT) have been commissioned to

support those early feeding experiences and prevent feeding aversions. The funding, allows for specialist feeding plans and observations to take place under supervision, assess safety of swallow; prevent feeding issues developing; support for feeding aversion and sensory based feeding disorders (Harding et al., 2019). Once discharged from the unit the lack of commissioned services in outpatient care often results in delayed appointments, delays in treatment, potential feeding issues and raised parental anxieties. The BSTL programme does recognise the need for these services, they have been commissioned and written into the plan. Unfortunately, the focus of SALT within the programme is age 3-4 years and school readiness. The opportunity for that early intervention and support is missed in those vital first months to possibly prevent inequalities in health and development. Longer term issues such as delayed speech, language and communication can affect school readiness and educational needs. Again, this lack of early intervention could impact on the family and those 'critical 1001 days' that shape the future of the family (Hancock, 2021).

The programme addresses the importance of tasks such as registration of a baby. Registering the birth of a baby is a legal requirement and needs to take place within the first 42 days from birth (www.gov.uk). The registration needs to take place at the local register office for the area the baby was born in. With many parents finding themselves in a hospital during much of these initial days, the convenience of having a local hub offering this service would be greatly welcomed for many. Registering baby also allows the parents/carers to claim benefits covering the North East of England we have a huge proportion of deprivation, for many families these benefits are vital in the health and wellbeing of the child and family.

The family hubs, single point of access, would give families the opportunity for peer support, with likeminded people and shared experience. The BSTL highlights the importance of reducing the times that

parents have to repeat their traumatic experiences to multiple health professionals. Burger et al., (2015) found only half of the correspondents were given information about support available once they were discharged from the Neonatal unit. With many Neonatal units not having a specific Neonatal outreach service and a variation of levels of availability throughout the UK, specialist support once discharged is often limited. Popescu (2021) acknowledged the need for continuing support once discharged from a neonatal unit and the need of developmental follow up. The Royal Foundation (2022) found that new parents with additional needs including those with preterm infants found that 73% of parents surveyed, were finding this new situation very stressful, again contributing to poor mental health. Popescu (2021) warns that raised anxiety levels stemming from preterm birth can lead to mixed emotions for both parents often compared to a 'roller-coaster'. Popescu (2021) continues by suggesting that lack of integrated services enhanced these emotions resulting in overprotective parents. The uncertainty, lack of direction and support could then result in parents/carers turning to inappropriate services such as accident and emergency causing an extra burden on the NHS.

The integration of health professionals is paramount to the future of the infant, especially those with additional needs (Gough *et al.*, 2014). Staff working in collaboration need an understanding of the needs of the infant and the family. The BSTL highlights the need for professionals to have an understanding in their needs and the right skills to help and support the family. The family hubs can connect people together and can be a support network for teams with the same goals. The health visitor plays a huge part in the family support network, they will be the consistent stakeholder during this identified time. Fenton & Gilroy (2020) discuss the importance in the role of the health visitor, as many parents rely on the primary health care team once discharged from the Neonatal unit. In 2019, charity 'Tiny lives' carried out a survey exploring the level of support

available from the health visitor once discharged from the Neonatal unit. The survey highlighted the need for extra education for health visitors around caring for these vulnerable families and highlighting the need for extra support and understanding. It is vital that the health visitor is given the tools to signpost families to appropriate, local support when the families need it. Fenton & Gilroy (2020) identify the need for Health Visitors to adopt a 'train the trainer approach' and have specific Neonatal family ambassadors to enable them to effectively support the families to have the best start in life.

The BSTL offer suggests that every family should be made aware of their local offer as soon as possible. This could be a family hub that is within walking distance or in those more rural areas an alternative method of support such as virtual groups. Families should be encouraged to access the support network and information about joining groups/advisory panels. Representation from the families that have that lived experience of Neonatal care on parental advisory panels, could enhance the project. Examples of good practice should be disseminated among localities so that each local offer can facilitate support according to the local needs. Data should be gathered with measurable outcomes, but also rich qualitative parental research would give an understanding of the holistic values of Neonatal community support.

The BSTL focuses on more joined up services, it is suggested that every family deserves a collaborative approach with clear accountability, ensuring that the family receives the right information at the right time. As the NHS core values suggest, working together to provide care for all patients allowing to improve lives and incorporating everyone without inequalities. Within the report it is suggested that failing to invest in this early recognition and support will result in expensive future consequences. Not only will this initial investment have immediate support for families right from discharge but could also have a greater insight to school readiness and the need for additional support provision.

It is also suggested that by implementing early intervention this will in turn contribute towards the levelling up agenda. The Levelling up Agenda (2022) recognises inequalities in health, education and social care and suggests that the UK is one of the most unequal countries in the world. The aim of the Levelling up Agenda (2022) is to ensure that whatever your background, there are equal opportunities to have a fulfilling, happy and productive life. With the introduction of the BSTL programme, children who have been identified as higher risk of disability should be offered support from the start. This will help to identify needs at an earlier stage and allow for provision to maximise the quality and standard of life. Early Intervention Foundation (2018) found that there was a clear need for effort to co-ordinate work of all departments and agencies to create a strong national voice to help shape life chances with focus on those whom are at risk of poor levels of achievement.

Conclusions

Knauf (2020) explains why the initial days, time, weeks, months and years in a child's life are so important, this being a crucial for development but it is also a time when they are at their most vulnerable. The BSTL programme is a wonderful beneficial initiative with the aim of joining up services and stakeholders, with the family being at the centre. The neonatal families are vulnerable, they have a significant risk of developmental delay (NICE, 2017) and increased risk of parental mental health issues. Knauf (2020) suggests that investing in these early years will shape the way of society in the future. The BSTL programme aims to address some of these issues and is currently being trail blazed in 75 local authorities. At little extra cost to the programme, an inclusive offer for Neonatal families could potentially reduce health inequalities, parental anxiety and improve longer term mortality and school readiness.

Each local offer should have services to support disabled or seriously ill babies and this includes those born preterm, the report suggests that this means finding ways of improving earlier identification of additional needs

(Knauf,2020). By initiating a local offer that is inclusive of every child and available to all families, support can be given to tackle those initial hurdles such as feeding and bonding but also link to Special Educational Needs and Disability (SEND) services. Ko (2015) discusses the importance of a person centred approach, agencies working together and specifies that the health service have an important role in early notification in preparation for the future of the individual. This would help to identify those needs early and offer appropriate educational provision.

Recommendations

As each locality authority offer different drivers, it is important that the Neonatal community is included in the planning and implementing of the BSTL service provision.

Each local offer should have:

- Peer support exclusively for Neonatal families
- Tools and education to deliver a tailored pathway for Neonatal Families
- Support from local and National charities
- Single point of Access
- Access to the right information at the right time
- Collaborative working with NHS, social care, Education and Allied professional

Reference List

Bliss (2023) Neonatal Care Statistics Available at:
<https://www.bliss.org.uk/research-campaigns/neonatal-care-statistics>
(Accessed 16th November 2023)

Burger, S, A.,King, J.,Tallett,A (2015) Parents experience of Neonatal care in England. Patient Experience Journal Volume 2 (2).45-52

Children & Families Act 2014. Available at: [legislation.gov.uk](https://www.legislation.gov.uk) (accessed 23rd February 2024)

Gilroy,V.,Fenton,A (2020)Health Visitors role in supporting sick and preterm babies and their families.*Infant*. Vol 16(6)

Gough,S.,Dryden,S.,Wolff,T.,Williams,J (2014)Did we aim high enough? Will legislation lead to better results for disabled children? *Paediatric child health*: (24) 355-61.

Hames,J,L.,Gasteiger,C.,McKenzie,M,R.,Rowley,S.,Serlachius,A,S.,Juth,V., Petriel,K,J (2021) Predictors of parental stress from admission to discharge in the neonatal special care unit. *Child Care Health Dev*. 2021;47:243–251

Hancock,M (2021) Cited in: The best start for Life, A version for the first 1,001 critical days. Available at www.gov.uk/official-documents.(Accessed 4th January 2024)

Harding, C., Levin, A., Crossley, S. L., Murphy, R., Van den Engel-Hoek, L(2019) Effects of early communication intervention on speech and communication skills of preterm infants in the neonatal intensive care unit (NICU): a systematic review. *J Neonatal Nurs*;25:177-88.

Hua, W., Yuwen, W., Simoni, J,M.,Yan, J., Jiang, L(2020) Parental readiness for hospital discharge as a mediator between quality of discharge teaching and parental self-efficacy in parents of preterm infants. *J Clin Nurs*;29(19- 20):3754-3763

Ko,B (2015) Education Health and Care Plans: a new scheme for special educational needs and disability provisions in England from 2014. *Paediatric child health*: (25)440-49

Levelling up agenda (2023) Available at: levellingup.campaign.gov.uk. (accessed 4th January 2024)

National Institute of Health Care and Excellence. Developmental follow-up of children and young people born preterm (NICE Guideline NG72).

Available at: www.nice.org.uk/guidance/ng72 (accessed 15th November 2023)

Ockenden Report (2022) Findings, conclusions and essential actions from the independent review of maternity services at The Shrewsbury and Telford Hospital NHS Trust. Available at: Ockendenmaternityreview.org.uk (accessed 16th November 2023)

O'Higgins, M., et al. (2013) Mother-child bonding at 1 year; associations with symptoms of postnatal depression and bonding in the first few weeks, *Archives of women's mental health*, 16(5), pp.381-389

Popescu, O, A, M (2021) A mixed methods study of the follow up of extremely preterm babies in the North East of England Available at: [1091 A mixed methods study of the follow up of extremely preterm babies in the North East of England | Archives of Disease in Childhood \(bmj.com\)](https://doi.org/10.1136/bmj-2021-032191) (accessed 21st February 2024)

Public Health England. (2020) No child left behind. A public health informed approach to improving outcomes for vulnerable children. Available at: [No child left behind: understanding and quantifying vulnerability \(publishing.service.gov.uk\)](https://www.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/871427/no-child-left-behind-understanding-and-quantifying-vulnerability.pdf) . Accessed 11th February 2024

The Royal Foundation (2023) Building Foundations for life. Available at: royalfoundation.com (accessed 4th January 2024)

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